

SECOND REGULAR SESSION
HOUSE COMMITTEE SUBSTITUTE FOR
HOUSE BILL NO. 1807
97TH GENERAL ASSEMBLY

5839H.02C

D. ADAM CRUMBLISS, Chief Clerk

AN ACT

To repeal section 191.331, RSMo, and to enact in lieu thereof one new section relating to newborn screening tests.

Be it enacted by the General Assembly of the state of Missouri, as follows:

Section A. Section 191.331, RSMo, is repealed and one new section enacted in lieu thereof, to be known as section 191.331, to read as follows:

191.331. 1. Every infant who is born in this state shall be tested for phenylketonuria and such other metabolic or genetic diseases as are prescribed by the department. The test used by the department shall be dictated by accepted medical practice and such tests shall be of the types approved by the department. All newborn screening tests required by the department shall be performed by the department of health and senior services laboratories. **Each birthing hospital or birth center in the state shall designate an employee to be responsible for the newborn screening program in that institution.** The attending physician, certified nurse midwife, public health facility, ambulatory surgical center or hospital shall assure that appropriate specimens are collected **and all information requested is provided on the newborn screening collection forms purchased from the department** and submitted to [the department of health and senior services laboratories] **the appropriate courier service pickup location as soon as the specimens are dry, which shall be a minimum of three hours from the time of collection, and no later than within twenty-four hours of collection in order to be transported to the department of health and senior services laboratory by the next scheduled courier pickup. If courier service is not available at the facility or at a location nearby, then first-class mail or other appropriate means can be utilized within the same time constraints for the sending of the specimens.**

EXPLANATION — Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

2. Specimens shall be collected in accordance with instructions on the specimen collection form. The timing of specimen collection shall be determined by the conditions specified as follows:

(1) A specimen shall be taken from all infants before being discharged from the hospital or birthing facility regardless of age. A specimen collected between twenty-four and forty-eight hours of age is considered optimum for newborn screening. A second or repeat specimen shall be required within fourteen days of age if the initial specimen was collected before twenty-four hours of age;

(2) Initial specimens from ill or premature infants shall be collected before a blood transfusion or between twenty-four to forty-eight hours of age. All ill or premature infants shall have a repeat screen collected between seven to fourteen days of age;

(3) If an infant has been transferred from one hospital to another, the records shall clearly indicate if a specimen for newborn screening was collected and submitted. If no specimen was collected, the hospital the infant was transferred to shall collect a specimen and submit it within forty-eight hours of the transfer.

3. All physicians, certified nurse midwives, **certified professional midwives, lay midwives**, public health nurses and administrators of ambulatory surgical centers or hospitals shall report to the department all diagnosed cases of phenylketonuria and other metabolic or genetic diseases as designated by the department. **The health care provider caring for an infant with an abnormal high-risk test report from newborn screening shall report a definitive diagnosis within thirty days of the date of diagnosis for such infant to the appropriate newborn screening follow-up center as contracted by the department.** The department shall prescribe and furnish all necessary reporting forms.

[3.] 4. The department shall develop and institute educational programs concerning phenylketonuria and other metabolic and genetic diseases and assist parents, physicians, hospitals and public health nurses in the management and basic treatment of these diseases.

[4.] 5. The provisions of this section shall not apply if the parents of such child object to the tests or examinations provided in this section on the grounds that such tests or examinations conflict with their religious tenets and practices.

[5.] 6. As provided in subsection [4] 5 of this section, the parents of any child who fail to have such test or examination administered after notice of the requirement for such test or examination shall be required to document in writing such refusal. All physicians, certified nurse midwives, **certified professional midwives, lay midwives**, public health nurses and administrators of ambulatory surgical centers or hospitals shall provide to the parents or guardians a written packet of educational information developed and supplied by the department of health and senior services describing the type of specimen, how it is obtained, the nature of

54 diseases being screened, and the consequences of treatment and nontreatment. The attending
55 physician, certified nurse midwife, **certified professional midwife, lay midwife**, public health
56 facility, ambulatory surgical center or hospital shall obtain the written refusal [and] , make such
57 refusal part of the medical record of the infant, **and send a copy of the written objection to the**
58 **department.**

59 [6.] 7. Notwithstanding the provisions of section 192.015 to the contrary, the department
60 may, by rule, annually determine and impose a reasonable fee for each newborn screening test
61 made in any of its laboratories. The department may collect the fee from any entity or individual
62 described in subsection 1 of this section in a form and manner established by the department.
63 Such fee shall be considered as a cost payable to such entity by a health care third-party payer,
64 including, but not limited to, a health insurer operating pursuant to chapter 376, a domestic
65 health services corporation or health maintenance organization operating pursuant to chapter 354,
66 and a governmental or entitlement program operating pursuant to state law. Such fee shall not
67 be considered as part of the internal laboratory costs of the persons and entities described in
68 subsection 1 of this section by such health care third-party payers. No individual shall be denied
69 screening because of inability to pay. Such fees shall be deposited in a separate account in the
70 public health services fund created in section 192.900, and funds in such account shall be used
71 for the support of the newborn screening program and activities related to the screening,
72 diagnosis, and treatment, including special dietary products, of persons with metabolic and
73 genetic diseases; and follow-up activities that ensure that diagnostic evaluation, treatment and
74 management is available and accessible once an at-risk family is identified through initial
75 screening; and for no other purpose. These programs may include education in these areas and
76 the development of new programs related to these diseases.

77 [7.] 8. Subject to appropriations provided for formula for the treatment of inherited
78 diseases of amino acids and organic acids, the department shall provide such formula to persons
79 with inherited diseases of amino acids and organic acids subject to the conditions described in
80 this subsection. State assistance pursuant to this subsection shall be available to an applicant
81 only after the applicant has shown that the applicant has exhausted all benefits from third-party
82 payers, including, but not limited to, health insurers, domestic health services corporations,
83 health maintenance organizations, Medicare, Medicaid and other government assistance
84 programs.

85 [8.] 9. Assistance under subsection [7] 8 of this section shall be provided to the
86 following:

87 (1) Applicants ages birth to five years old meeting the qualifications under subsection
88 [7] 8 of this section;

89 (2) Applicants between the ages of six to eighteen meeting the qualifications under
90 subsection [7] 8 of this section and whose family income is below three hundred percent of the
91 federal poverty level;

92 (3) Applicants between the ages of six to eighteen meeting the qualifications under
93 subsection [7] 8 of this section and whose family income is at three hundred percent of the
94 federal poverty level or above. For these applicants, the department shall establish a sliding scale
95 of fees and monthly premiums to be paid in order to receive assistance under subsection [7] 8
96 of this section; and

97 (4) Applicants age nineteen and above meeting the qualifications under subsection [7]
98 8 of this section and who are eligible under an income-based means test established by the
99 department to determine eligibility for the assistance under subsection [7] 8 of this section.

100 [9.] 10. The department shall have authority over the use, retention, and disposal of
101 biological specimens and all related information collected in connection with newborn screening
102 tests conducted under subsection 1 of this section. The use of such specimens and related
103 information shall only be made for public health purposes and shall comply with all applicable
104 provisions of federal law. The department may charge a reasonable fee for the use of such
105 specimens for public health research and preparing and supplying specimens for research
106 proposals approved by the department.

107 **11. If any person or entity has reason to believe that a physician, certified nurse**
108 **midwife, public health facility, ambulatory surgical center, or hospital has violated a**
109 **provision of this section, such person or entity shall file a complaint with the department.**
110 **Upon receipt of such a complaint, the department shall conduct an investigation of the**
111 **suspected physician, certified nurse midwife, public health facility, ambulatory surgical**
112 **center, or hospital.**

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